Getting end of life care right in primary care

Dr Bill Hulme, St Leonards Hospice
Dr Dan Cottingham, GP
Kath Sartain, End of life lead nurse, YTHT

Why?

- 1% of your practice population will die in the next 12 months
  - Do you know who they are?
- Increased health & social care utilisation in last year of life
  - economic cost,
  - patient preferences
  - informal carer burden
- Multi-agency working – needs communication and co-ordination

Getting it right....

- Patients more likely to die where they want
  - Avoid inappropriate investigations, treatments, admissions
- Access to services and symptom control medication
- Carer support
- Bereavement support

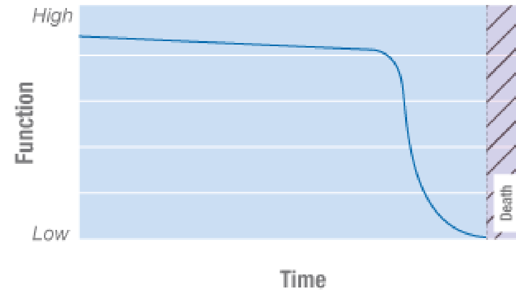
Why? (£.....)

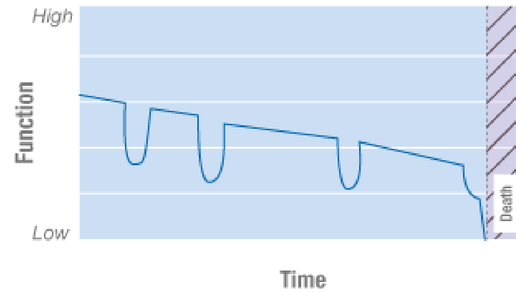
Indicator	Points
QI003: The contractor can demonstrate continuous quality improvement activity focused on end of life care as specified in the QOF guidance	27

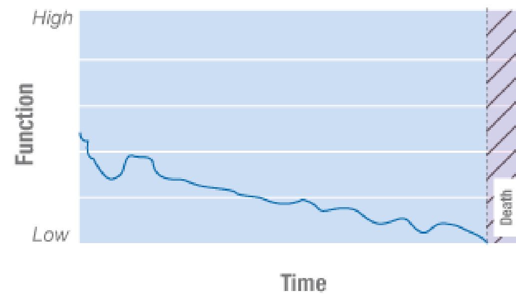
Quality improvement measures

- 1. **Early identification and support for people** with advanced progressive illness who might die within the next twelve months.
- 2. **Well-planned and coordinated care** that is responsive to the patient’s changing needs with the aim of improving the experience of care.
- 3. **Identification and support for family / informal care-givers**, both as part of the core care team around the patient and as individuals facing impending bereavement.

'Identify' exercise







Care Plan for the Last days of Life (CPLDL)

Doctor's Booklet

Patient name:
Hospital no:
NHS no:
D.O.B:

or affix patient ID sticker here

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Last Days of Life Documentation

Agreed contacts for the patient			
1st contact name:		2nd contact name:	
Relationship to the patient:		Relationship to the patient:	
Tel No:		Tel No:	
Mobile No:		Mobile No:	
Agreed to be called at night Yes ☐ No ☐		Agreed to be called at night Yes ☐ No ☐	

Useful Contact Numbers				
	York		Scarborough	
	Hospital Monday to Sunday 08:00-16:00	**Community** Monday to Sunday 08:30-16:30	**Hospital** Monday to Sunday 08:30-16:30	**Community** Monday to Friday 08:30-16:30
Palliative Care Team	01904 725835	01904 724476	01723 342446	01723 356043
Medicines Information	01904 725960	0191 2824631	01723 385170	0191 2824631
Tissue Donation	08004320559			
Organ Donation	07659171979			
Bereavement Information	01904 725445 (5 day service)		01723 385178 (5 day service)	
For "out of hours" symptom control advice contact				
Scarborough	"Palcall", St Catherine's Hospice, Scarborough: 01723 354506			
York	St Leonard's Hospice, York: 01904 708553			

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1. Decision making

- Doctor's section with white space to document conversations
  - Patient may be dying and likely course of events
  - DNACPR
  - Hydration and nutrition
  - Syringe driver (requires consent)
  - Rationalise drugs

2. Care plan

- Initiation by doctors and
- Symptom check completed usually by nurses
- **Ongoing documentation in medical notes**

3. Documentation after death

- all deaths

Symptom control

- Laminated algorithms
- Opioid conversion chart on back of syringe driver chart

Decision making: part of an MDT

Decision making in last days of life
Professional leading the decision making process to complete all pages

Communication
Is an interpreter required? Yes ☐ No ☐
Interpreter Tel. No.
Any barriers to communication? If Yes, please state:

Mental Capacity
Patient has capacity to make decisions about treatment? Yes ☐ No ☐
If No, has a mental capacity assessment been completed? Yes ☐ No ☐
(available in DNACPR folder)

Advance Care Planning (ACP)
In the event of limited or no capacity does the patient have:
An Advance Care Plan? Yes ☐ No ☐
A valid Advance Decision to Refuse Treatment (ADRT) Yes ☐ No ☐
A valid Lasting Power of Attorney for Health Matters? Yes ☐ No ☐
Contact details:

Wishes
An expressed wish for:
Organ/Tissue donation? Yes ☐ No ☐
Donation of body to medical science? Yes ☐ No ☐
Have forms been completed? Yes ☐ No ☐

Preferred Place of Death (PPD):
Has the patient expressed a PPD? Yes ☐ No ☐
Usual place of residence Home or care home ☐ Hospital ☐ Hospice ☐
Other ☐ Specify:

Initial Assessment

Nutrition and Hydration Assessment
Document discussions and decision made in individualised care plan
a) Clinically Assisted (artificial) Hydration (CAH)
Is the patient's thirst persistent? Yes ☐ No ☐
If Yes, consider CAH
b) Clinically Assisted (artificial) Nutrition (CAN) Yes ☐ No ☐
c) Is patient Nil by Mouth (NBM)? Yes ☐ No ☐
If Yes, document why e.g. unsafe swallow
Who made NBM decision?

DNACPR
Is a DNACPR decision in place? Yes ☐ No ☐
If No discuss with patient and/or relevant others, document conversation and complete DNACPR form

ICD
Is an Implantable Cardioverter Defibrillator (ICD) in place? Yes ☐ No ☐
Has it been deactivated? Yes ☐ No ☐
If no plan in place for deactivation, please contact cardiology for decision to deactivate.

Decision making (Recognise, communicate, involve, support and plan) (RCISP)

Diagnosis

Recognise the patient may be dying. Have all reversible causes been considered? What indicators have been identified? i.e. reduced responsiveness, daily deterioration, reduced daily oral intake.

See next slide on guidance how to complete

Communicate, involve and support patient, family, persons important to patient including spiritual support. Document names of patient/family and healthcare professionals present.

Who was involved?

What was discussed?

Any unresolved issues?

Detail any spiritual needs:

Individualised Plan: Document following discussions: food and fl... made decision, rationalising medications, observations and investigations, pref... and anticipatory drugs. *If applicable diabetic and seizure management*

Recognise, Communicate, Involve, Support, Plan

Decision making (Recognise, communicate, i

Diagnosis

Recognise the patient may be dying. Have all reversible ca... identified? i.e. reduced responsiveness, daily deterioration, reduce

Metastatic breast ca

Recognise the patient may be dying. Have all reversible causes been considered? What indicators have been identified? i.e. reduced responsiveness, daily deterioration, reduced daily oral intake.

Document why you patient may be dying.

Advanced breast cancer with no further targeted cancer treatment. Daily deterioration with no reversible causes identified. Feeling much weaker and struggling to move In bed and take medications. Still able to take sips of fluid.

Communicate, involve and support patient, f... spiritual care. Document names of patient/family and healthcare prof...

Who was involved?

What was discussed?

Any unresolved issues?

Detail any spiritual needs

Communicate, involve and support patient, family, persons important to patient including spiritual care. Document names of patient/family and healthcare professionals present.

Who was involved?	Dr Smith and ward sister Jones met with patient X and her son and daughter.
What was discussed?	It was explained to patient x and family that she was very weak and unwell and not responding to current treatment plan or antibiotics and very unlikely to get better from this and thought to be dying. Patient and family understood. Focus of care now switched to comfort measures and treating symptoms .
Any unresolved issues?	
Detail any spiritual needs	Not religious and doesn't want to see a chaplain

Individualised Plan: Document following discussions: ... made decision, rationalising medications, observations and investig... and anticipatory drugs. *If applicable diabetic and seizure managem...*

Individualised Plan: Document following discussions: food and fluids, if nil by mouth state reason and who made decision, rationalising medications, observations and investigations, preferred place of death, use of syringe driver and anticipatory drugs. *If applicable diabetic and seizure management*

Discussed as patient x not able to take oral medication her drugs would be rationalised. I explained may need injectable drugs that would be written up in anticipation and may also need a syringe driver and explained what this was. Fluid would be offered orally if able to take.

Established patient would prefer to spend her last days in hospital.

Symptom checklist

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Symptom Observation Chart for the Dying Patient

Patient name:
Hospital No:
NHS No.
D.O.B:

or affix patient ID sticker here

Date patient was recognised as dying: ___/___/_____

Record symptoms at least 4 hourly

Month	Date												
Year	Time												
Pain (reported or observed)	3												
	2												
	1												
	0												
Nausea	3												
	2												
	1												
	0												
Vomiting	3												
	2												
	1												
	0												
Breathless-ness	3												
	2												
	1												
	0												
Respiratory Secretions	3												
	2												
	1												
	0												
Dry Mouth	3												
	2												
	1												
	0												
Agitation/ Distress	3												
	2												
	1												
	0												
Other (state) -------	3												
	2												
	1												
	0												

HCA signature													
Registered nurse signature													
Doctor signature													

KEY - Please Consider:

3 = Symptom present, does not resolve with PRN medication	Repeat PRN and review after 30 minutes. Dr review, and referral to SPCT.
2 = Symptom present, requires PRN medication to resolve	Give PRN medication review after 30 minutes. Consider Dr review or advice from SPCT.
1 = Symptom present, resolves spontaneously	Give PRN medication. Consider adapting care plan for symptom.
0 = Symptom absent	Care plan continues

Please document any variances (page 3 and 4)

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Action and Evaluation of Symptoms

SYMPTOM (What symptom?)	ACTION (What did you do?)	EVALUATION (Did your action help? If not, what other action have you taken?)
Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______
Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______
Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______
Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______
Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______	Signature: ______ Date/Time: ______

Resources

- https://www.rcgp.org.uk/clinical-and-research/resources/a-to-z-clinical-resources/daffodil-standards.aspx
- NICE Quality Standards for End of Life Care in Adults (QS13) and Care of dying adults in the last days of life (QS144)
- Gold Standards Framework:

  www.goldstandardsframework.org.uk